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ABSTRACT

This report is one of three resulting from a 50-state survey on the development of family policies through the implementation of Public Law 99-457 (Part H) and focuses on the Interagency Coordinating Council (ICC), the participation of family members, parental access to services, the identification of family strengths and needs, and family participation in the Individual Family Service Plan (IFSP) meeting. Among findings were the following: parents were recruited for the ICC from such sources as agency recommendations and state parent groups; special attempts were made to recruit minority representation in most states; parents' participation was often financially assisted; half of the states allow families themselves to identify who is a family member; various methods are used to access services; informal interviews are most often used to identify family needs; families can usually bring others to the IFSP meeting; monitoring is the function of various entities including state or local lead agencies and case managers. It is concluded that, although few policies have been fully implemented yet, most states are making a "good faith" effort to meet the law's legal requirements. An appendix details the survey's methodology. Includes 4 references. (DB)

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Carolina Institute for Child and Family Policy

STATUS OF STATES' POLICIES THAT AFFECT FAMILIES: THE EARLY INTERVENTION SYSTEM P.L. 99-457, Part H The Infants and Toddlers with Handicaps Program

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FOREWORD

A Series of Reports on the Family and P.L. 99-457 (Part H)

One of the clearest objectives of the framers of P.L. 99-457 (Part H) was their special concern for families. The intent to strengthen the family's role in planning for their own child is manifest in their expected participation in the Individual Family Service Plan, in the provision of procedural safeguards, the requirement that three parents service on the Interagency Coordinating Council, and the case management requirements to provide a single communication point for the family in its dealing with the professionals providing service for their child.

Legislative intent is one thing and the actual policy development and implementation that follows from the legislation can be something quite different. The Carolina Policy Studies Program undertook this study in an attempt to understand what the states were actually doing to put these ideas into practice.

The Carolina Policy Studies Program (CPSP), through a subcontract with the National Association of State Directors of Special Education (NASDSE), conducted a fifty-state survey in early Fall of 1990 on the development of family policies through the implementation of PL 99-457 (Part H). The survey addressed questions of family involvement in Interagency Coordinating Council activities, how families access the service system, how case management policies affect families, and what policies provide for procedural safeguards. Because of the quantity of data collected, these results are in three separate reports.

This first report, "Status of States' Policies that Affect Families: The Early Intervention System," deals with the ICC and the participation

of family members, parental access to services, the identification of family strengths and needs and family participation at the IFSP meeting. A second report, "States of States' Policies that Affect Families: Procedural Safeguards," deals with policies regarding consent, confidentiality, access to records, and dispute resolution. The final survey report, "Status of States' Policies That Affect Families: Case Management," deals with the selection of case managers, qualifications and training of case managers, vehicles to monitor and supervise case managers and financing the case management system.

The free reports of findings from this survey are available in reports from the Carolina Policy Studies Program, University of North Carolina at Chapel Hill, 136 E. Franklin Street, Chapel Hill, N.C. 27514. Refer to one of the following:

Place, P., Gallagher, J., & Eckland, J. (1991). Family Policies in State Programs for Infants and Toddlers with Handicaps: The Early Intervention System. Chapel Hill, N.C.: Carolina Policy Studies Program.

Place, P., Gallagher, J., & Eckland, J. (1991). Family Policies in State Programs for Infants and Toddlers with Handicaps: Procedural Safeguards. Chapel Hill, NC: Carolina Policy Studies Program.

Anderson, K., Place, P., Gallagher, J., & Eckland, J. (1991). Family Policies in State Programs for Infants and Toddlers with Handicaps: Case Management. Chapel Hill, N.C.: Carolina Policy Studies Program.

EXECUTIVE SUMMARY

This report on family policy developed from P.L. 99-457, (Part H) is the first of three that details the results of a telephone interview survey of the fifty state Part H Coordinators. The first report focuses on policies related to parental ICC activities, the definition of "family", the methods needed to identify family needs, Individual Family Service Plan (IFSP) policy, and monitoring responsibilities for the IFSP.

ICC and Family Policy

The law mandates that at least three parents serve on the Interagency Coordinating Council and the survey attempted to discover how such parents were identified and what incentives were offered to insure participation.

* Parents were Recruited for the ICC from a variety of sources including recommendations from providers or agencies (39 states), state parent groups (24 states), universities (6 states), and public announcements (6 states).
* Special attempts were made to recruit minority representation in most states.
* Support of the parents' participation was assisted by providing reimbursed travel costs (49 states), child care expenses (33 states), direct payment for services (14 states), etc.
* No state considered siblings or other family members as potential candidates for ICC membership because of that relationship and few systematically solicited input from them.

Policies Regarding Parental Access to Services

Some of the troublesome questions facing policy makers are: Who are members of a family? How is a family defined? How can the family access services? How does one assess families strengths and needs? What is the family input on the IFSPs? How will the delivery of services be monitored?

* Half of the states dismissed the issue of family definition by allowing the families themselves to identify who is a family member. Two states defined the family as the child's primary care takers and five states had other definitions such as, "persons who reside in the domicile". However, 18 states still don't know how or if they will define family.
* A variety of methods are or will be used in states to access services. The family may call an "800" number (36 states), call a specific person at a local level (18 states) or at a regional level (23 states), or call ICC members (2 states).
* The favored method to identify family needs was the informal interview (22 states), more structured assessments were in the next most frequent choice (9 states), while informal observations were named seven times and formal interviews were preferred in two states.

IFSP Procedures

Decisions about services which the family will receive must be developed by an IFSP team, of which the family is to be an important member. The survey identified some issues about the decisions regarding services and the implementation of the IFSP.

* There was strong agreement among the states that the family could bring anyone they wished to the IFSP meeting. If there

was disagreement between professionals and parents over needed services, most states relied upon the IFSP team to work it out; the state lead agency was given the ultimate decision in 10 states, and there was a miscellaneous collection of other solutions, including nine states that still had no policy on resolving IFSP conflicts.

* The responsibility for monitoring also brought forth a great diversity of proposed policies. The state lead agency was mentioned by 21 states, while another 11 states noted a local or regional lead agency, 11 states wanted a cooperative responsibility between lead agency and another entity, and the case managers carried the responsibility in six states.

The requirement of family empowerment in this law has put many additional responsibilities on policy makers. From this survey, there appears to be general willingness to involve families in decision making and the problems center around choosing the appropriate mechanisms to achieve that goal. There appears to be a minimum of resistance to most of these changes and an acceptance of the central role to be played by the family.

Few of these policies have been put into place or into operation. It seems clear that the states are going to be in an era of trial and error and many of these policy statements or decisions may be modified or changed by the direct experience of service delivery personnel. At the present time, most of the states appear to be making a strong "good faith" effort to meet the requirements of the law in this domain.

INTRODUCTION

The CPSP studied states' development of policies for the Part H, Infant and Toddlers Program. This legislation (P.L. 99-457) targeted the family of the infant or toddler with special needs as a primary decision-maker about and potential recipient of early intervention services. CPSP investigated the involvement of families in the development of policies for the Part H program, e.g., by identifying families' involvement with the state Interagency Coordinating Council. The Institute is also very interested in studying the policies which are likely to impact directly on the families of these very young children. As part of these multiple study efforts, CPSP conducted a telephone survey of Part H coordinators in 50 states to collect data on these topics. A complete description of the methods used to conduct the survey is contained in Appendix A.

RESULTS

ICC & Family Policy

Recruitment of ICC parents. One goal of this study was to determine how states recruited parents to participate on the ICC. The Part H statute requires three parents be appointed to each state's ICC. Were states aggressive in recruiting parents? Did they adopt methods to target the recruitment of representatives of minority cultures? Were there attempts to solicit input from family members other than parents? Answers to these questions might depict the importance the state places on parent and family participation in policy development and approval.

States reported using a variety of mechanisms to recruit parents. Most states (32) reported using more than one strategy. The strategy that was reported most often, by 39 states, was recruiting from providers or agencies. Almost half the states (24) solicited recommendations from a

state parent group. In addition to these strategies, six states reported recruiting from universities and six states relied on public announcements of some kind. In addition, 20 states reported using one or more other methods, such as asking existing ICC parent representatives or local ICCs for suggestions.

Almost every state made special attempts to recruit representatives of minority populations. The most typical strategies used included recruiting from service providers and local ICCs and making announcements to minority populations and leadership. A variety of anecdotes were offered to elaborate on the mechanism used to identify and retain parents from minority populations, e.g. one state paid for the parent to take a taxi to the meeting, at a cost of approximately $70. However, coordinators often expressed concern that, despite these strategies, they were unable to recruit and/or retain minority parents.

Only five states systematically attempted to solicit input from other family members besides parents. Of the states that specified what strategies they used, one used pilot projects to solicit input from siblings, another held Family Outreach meetings, and the third invited family members to attend state sponsored family conferences. No state specified that they recruited siblings or other family members of people with disabilities to participate officially in planning or policy development.

All 18 states which have the SEA as the lead agency reported that the Governor was the official who appointed the parents, as was true for all but one of those states where Health is the lead. In that one state, the Commissioner from the lead agency appointed the Council. In the states which have "other" lead agencies, the governors make the appointments in 12, while six of these states have varying policies. Appointments in these

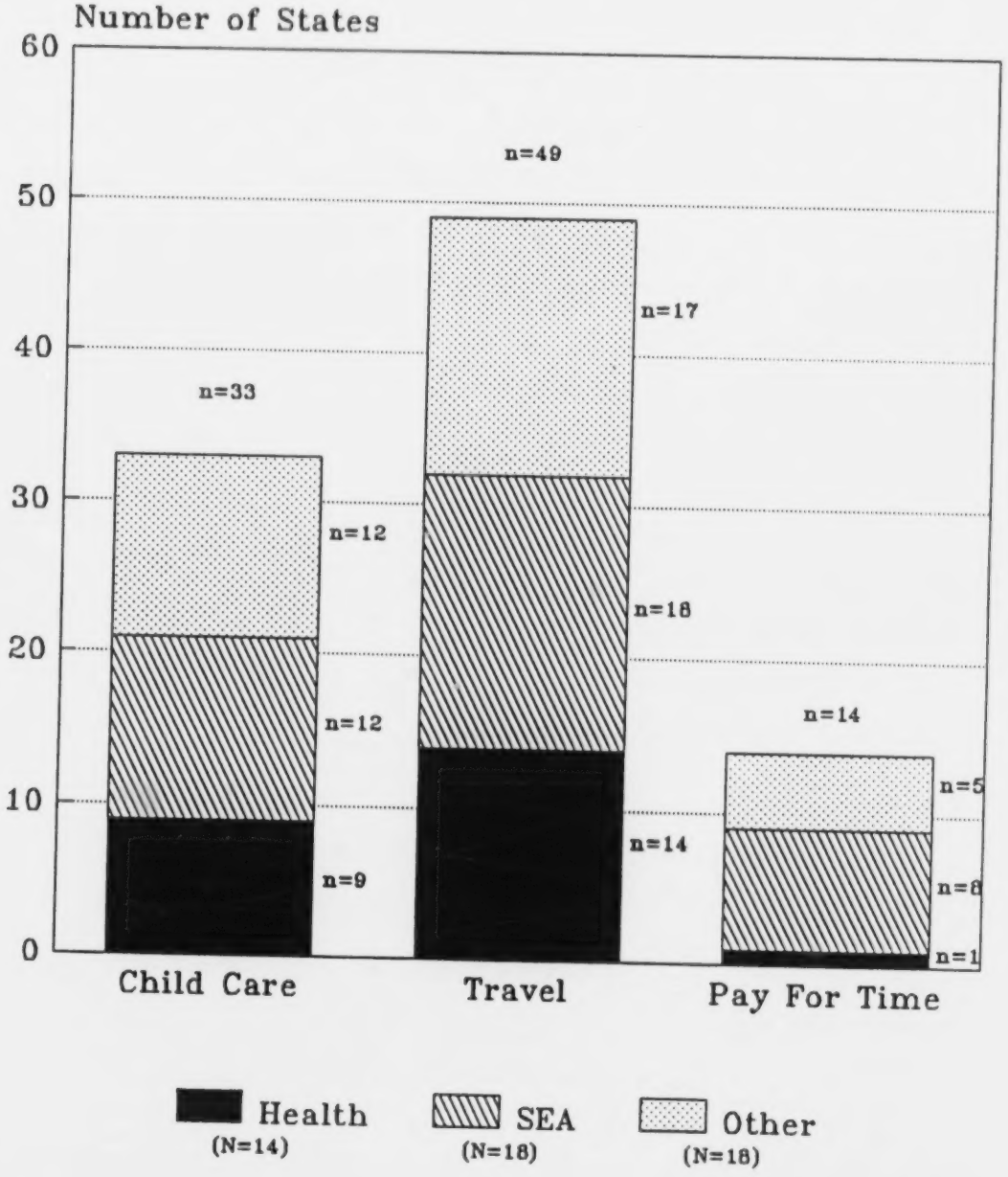
six states include: approval by the mayor, by the Senate, by the lead agency, and joint approval by the ICC chair and the Governor. One state reported that there was no formal appointment. "We take what we can get. Sometimes we get two parents and sometimes we get six." Thus, in 90 percent of the states, the appointment of the parent representative to the ICC is made by the Governor.

Support of ICC parents. State coordinators were asked to specify how their states supported the efforts of parents on the ICC. These data were collected to determine what mechanisms were used to help parents to function as ICC members. In addition, sharing this information might suggest new or different approaches to support parents. States support parents in many and varied ways. Fifty-eight percent of the states (29), reported providing three or more ways of supporting parents' involvement on the ICC or other state activities. Only six states reported a single mechanism of support. A typical policy is for states to pay for travel and child care expenses and reimburse for some other related costs as a method of supporting parental involvement on the ICC.

As Figure 1 demonstrates, most states pay for child care for parents serving on the ICC. Only two states provide on-site child care. Many states reported that they had offered this or would offer on-site child care but that parents did not want or use this option. The reasons cited for this were that parents preferred to use their regular baby sitters and that traveling with an infant or toddler was quite challenging.

All states except one stated that they paid for travel expenses for parents on the ICC. Some states reported paying parents for the time that they spent on ICC activities while a few states reported that state policies prohibited paying council members for their time. Payment for time was the only strategy which differed by lead agency. For the most

Figure 1
State Support of ICC Parents' Activities



part, Health lead agencies did not/could not make this option available to parents on the Council. Almost half (44 percent) of the states that had Other Lead Agencies paid for parents' time while a little more than a quarter of the SEA states provided this payment.

Half the states reported reimbursing parents for other expenses related to their activities on the part of the state, e.g., reimbursing costs for long distance telephone calls. Some of the additional strategies reported by states to support parents' activities included:

- pay a per diem rate while in travel status plus mileage or an airplane ticket;
- hire four parents with Part H funds as state employees to provide on-going and in-depth input and involvement;
- give an honorarium to parents to be be used on anything the parents want (three states);
- pay for lunch on full day sessions; parents can call the office collect;
- pay for attendance at out-of-state conferences;
- support parent participation at state conferences, including stipends for tuition and provide on-site day care; have crib, etc., available at ICC meetings for parents who want to bring children;
- mentor parents new to the ICC;
- help make arrangements for respite care but cannot pay for it.

Parental Involvement and the EI System

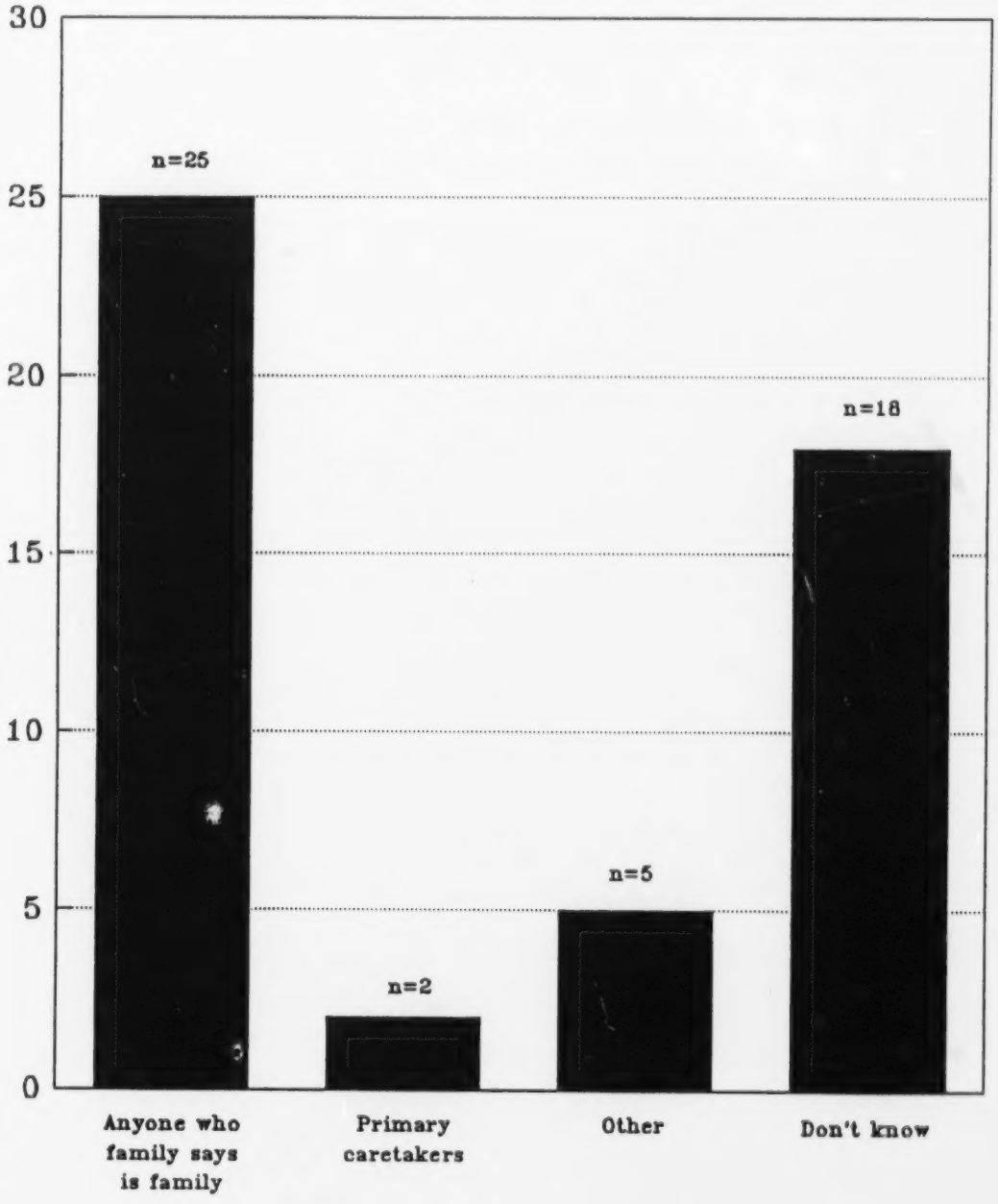
This section presents results which identify the policies regarding the relationship between the early intervention system and the individual family. The scope of the questions ranged from the state definition of a family, i.e., who is eligible under this program to receive Part H services, through entry into the system, and finally, decision-making about the IFSP. An additional question was asked about the policies for monitoring

the provision of the services included in the IFSP. If the system works well, families will not need to be involved in this activity but they are obviously impacted by the nature and success of these policies. An ideal IFSP which is not adequately implemented will have negative impacts on the child and family.

Definition of family. As displayed in Figure 2, half the states are planning to have policies that defined the family as anyone who the family says is a member of the family (6 = SEA, 10 = Health, 9 = Other). This definition of the family is official policy in the four states that have official policies. Two states anticipate having policies that define the family as the child's primary care takers. Five states had other definitions or categories of definitions, such as "biological and legal parents and persons who reside in the domicile". Approximately one-third, of the states (18) don't know how they will define family or if there will be an official state definition.

Access to Early Intervention. Coordinators were asked how parents could get into the early intervention system. Almost three-fourths of the states relied on multiple access routes. Each state identified at least one method, i.e., no state said they didn't have an idea about this policy. The most often mentioned technique cited by Part H coordinators (36 states) was for the family to call a toll free, i.e., an "800", number. The second most frequently cited action was to call someone at the local (19 states) or regional (23 states) level. These contacts might be service providers or lead agency personnel. Two states said parents could contact the ICC.

Figure 2
Definition of "Family"

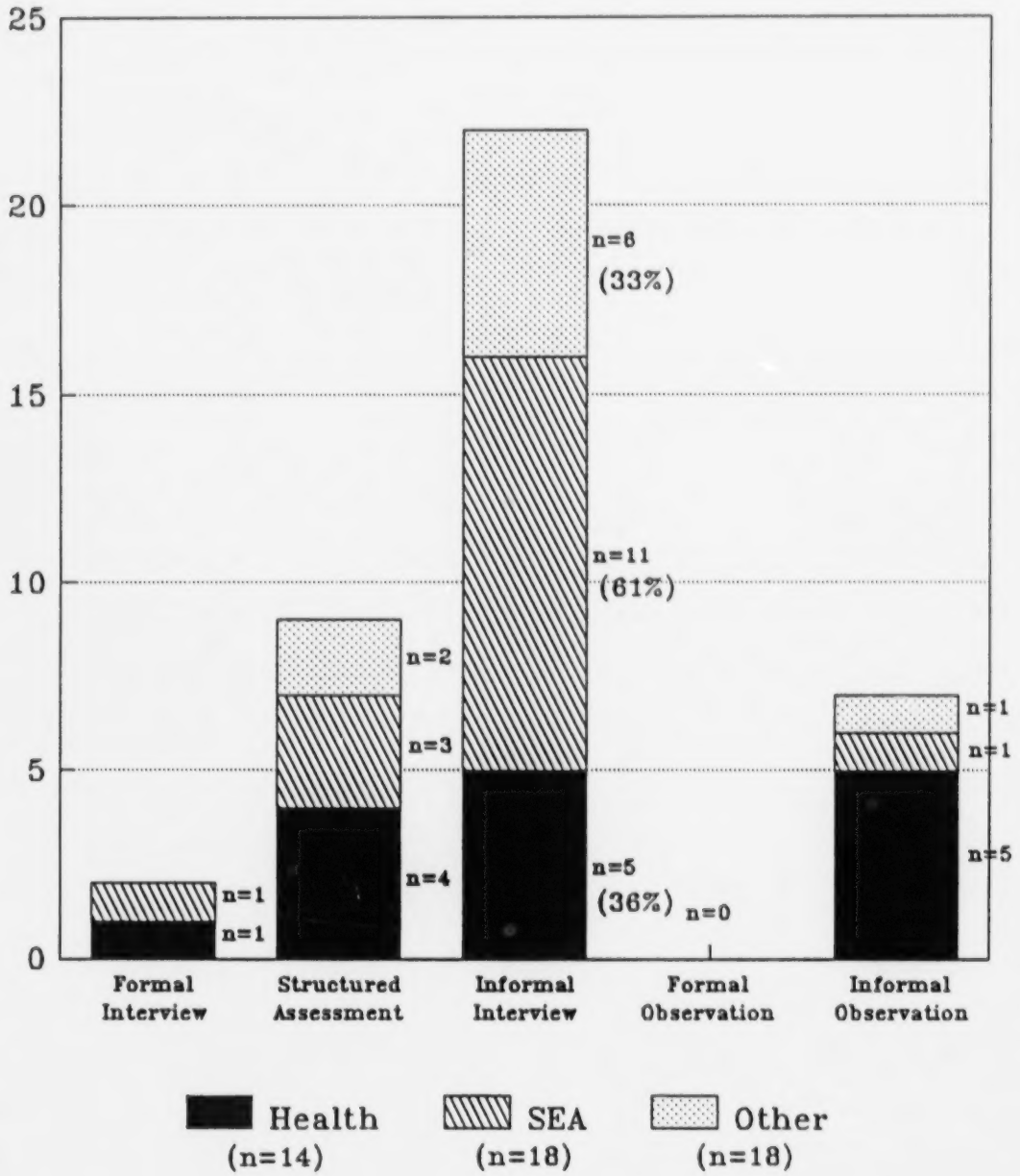


Additional methods by which to access the system cited by the coordinators included some which were very specific to the state. For example, one state said families could contact the "Advocacy Coordinator" and another said that "if parents call the state Child Care Resource Center the CCRC should refer the family to the early intervention system, if appropriate." Other methods cited included referral from disability groups, health agencies, or advocacy groups; and referral from other agencies. Two states indicated that access to the system would vary depending on policies at the local level.

Identifying family strengths and needs. The Part H coordinators were asked what were, or what were likely to be, their policies for identifying family strengths and needs. These responses were categorized and the results are presented in Figure 3. The plan in nine states is to leave this decision up to local discretion while six states did not know what their policies were likely to be in this area.

While some states identified more than one method, as Figure 3 shows, most coordinators said that states are planning to adopt policies to identify family strengths and needs which are primarily "informal" in nature. Approximately one-third of the states where Health or an Other agency is the Part H lead agency cited the desire to use these informal methods. Almost two-thirds of the states that have the SEA as the lead agency cited this method. Many coordinators asserted that this would be critical to insure that the identification process was not intrusive and was guided by the desires of the family. As a first contact with the early intervention system, many coordinators suggested, the tone of this early contact would set the tone for the following relationship between the family and the early intervention system.

Figure 3
Methods to Identify Family Needs

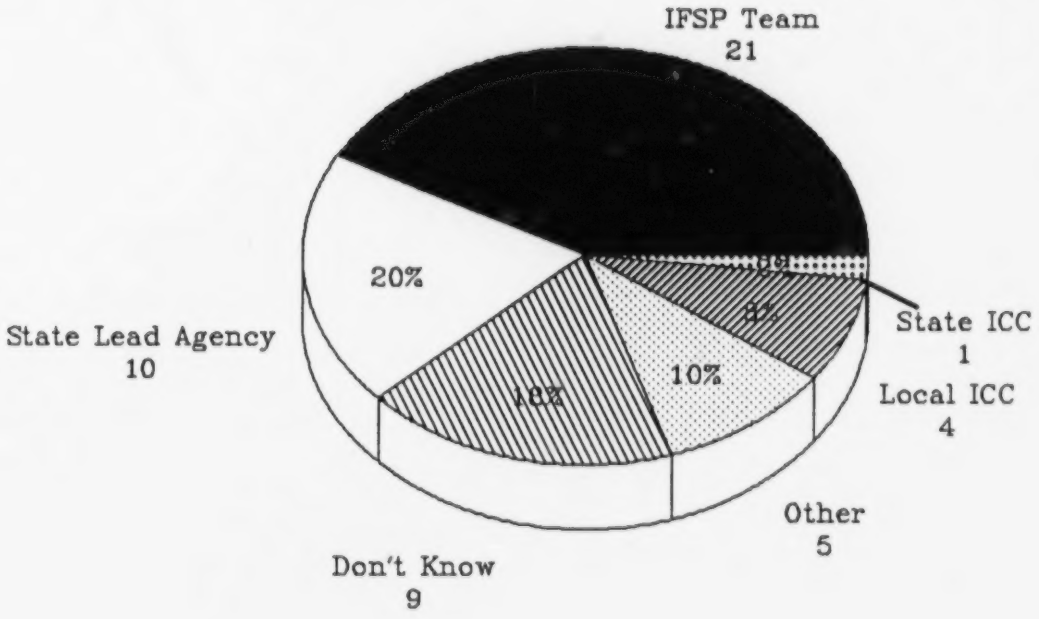


Attendance at IFSP meeting. When states were asked who the family could invite to the IFSP meeting, states that had policies (official or unofficial) in this area said the family could bring anyone they wanted to the meeting. Almost every state said that the parents, as part of the IFSP team, would participate in the decision about what services are listed on the IFSP.

The interviewer prompted and asked who would make the decision if the family wanted something listed as a service that was clearly beyond the scope of entitlement under the early intervention program. This proved to be a challenging question and some coordinators found it difficult to answer. Coordinators initially answered this question by saying that any service the family wanted should be listed on the IFSP. The coordinators indicated that they wanted to list all the services the family thought were important because they wanted to reinforce parents' desires and to document the need for various services. In addition, they feared disagreements about services would turn the IFSP meeting into a confrontational event rather than one which is supportive and family-focused.

However, decisions have to be made when there are conflicts and, after continued conversation about this, many coordinators identified various agency and ICC representatives as final decision-makers when conflicts arise during an IFSP meeting. As depicted in Figure 4, a little more than half of the 41 responses received indicated that, if there were differing opinions, the IFSP team would have to decide what services would be identified as services which the family was entitled to receive. Many coordinators emphasized that the family is a member of the team. Some coordinators added that the parents had mediation or other complaint resolution processes available if they disagreed with the

Figure 4
Ultimate Decision Re: IFSP Services



decisions of the majority of the team. Of the nine states that have official policies, seven said the team will decide.

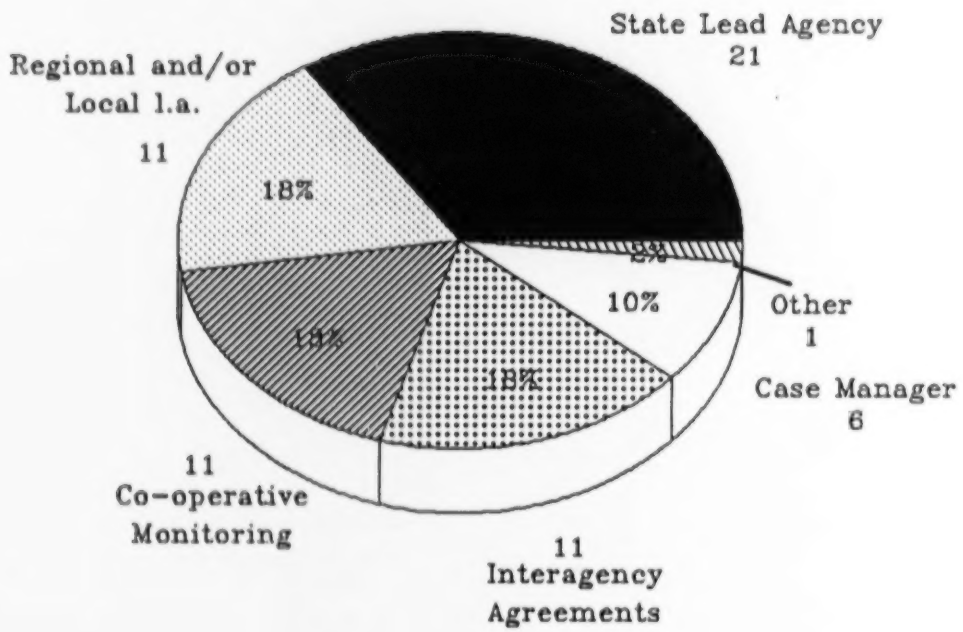
The remaining 20 states thought that their policies would include some additional, or back-up, approval mechanism(s) for such conflict situations. Of these, four states said atypical situations would be decided by the local ICC, one said these decisions would be resolved at the state ICC, and nine states said the decision would be made by the state lead agency (the official policy in two states).

One coordinator said that any service the family wanted on the IFSP would be written down but only services on a list of state-approved early intervention services would be paid for by the early intervention program. This state was included with the nine states where the decision is made by the state lead agency. In addition, five states said that the decision would be made by some other, i.e., the case manager, the program administrator, the Child Study Team, or a team of four agency coordinators at the state level. Nine states could not answer this question at this time.

Monitoring. Once services are identified and included in the IFSP, it is important to know who has the responsibility to assure the implementation of the IFSP. As stated previously, if the policies that guide the system are clear and well implemented, families will not need to be involved in monitoring. This topic was included in the survey, however, because policies which assure that the services listed on the IFSP are delivered to families have an obvious impact on families involved with the early intervention system.

Coordinators were asked who would monitor the delivery of these services (see Figure 5). Twelve states did not know who would monitor the delivery of services. Of the remaininh 38, all but four states

Figure 5
Monitoring Mechanisms



identified a specific role for the lead agency either at the state or regional level. Some states identified more than one method of monitoring so the sum of the data in Figure 5 exceeds the number of states surveyed.

State lead agency personnel were named as having the responsibility of monitoring the delivery of services in 21 states. In 17 states they were identified as the only intended source of monitoring. In 11 states this responsibility will be a cooperative activity between the lead agency and at least one other entity. Lead agency staff at the regional level will be involved in monitoring in 11 states, in four states they will be the sole monitors. In addition to the above mechanisms, interagency agreements were involved in the monitoring activities in 11 states. Case managers have this as a specified responsibility in six states.

Of the four states that did not specify a role in monitoring for the lead agency either at the state or regional level, three said that the monitoring of service delivery was the responsibility of the case manager. If the case managers are lead agency personnel, a clarification that was not included in the survey, then a role of the lead agency was identified in all but one of the states that responded to this item. That state said the agency delivering services would monitor itself and the state would also use a parent satisfaction survey (the official policy).

Of the eight remaining states with official policies, all but one specified a role for the personnel at the state level. This last state described a process where lead agency personnel at the regional level monitor the delivery of services. While almost all of the official policies include a role for the lead agency, monitoring mechanisms will vary from state to state. In addition to the state lead agency, three of these states will use co-operative monitoring. In one state, initial responsibility for

day-to-day monitoring is the responsibility of the case manager with overall monitoring being the responsibility of the lead agency. Roles were assigned in three states to regional lead agency staff as well as state lead agency staff, with one of these states including providers and/or parents as monitors.

DISCUSSION

ICC & Family Policy

The survey data strongly indicate that states are very interested in recruiting and supporting parents of young children with special needs to participate on the state ICC. The Part H coordinators described comprehensive recruitment strategies used to solicit recommendations for qualified representatives. Many anecdotes were offered to explain the variety of activities which coordinators utilized. As one coordinator explained, "We literally blanketed the state to get as wide an array of input as possible." The enthusiasm expressed by the coordinators to solicit appropriate representation seemed to go far beyond mere compliance with the statutory requirement. Serious attention was paid to recruiting from minority populations but coordinators often expressed dissatisfaction at the results of these attempts.

On the other hand, few states systematically solicited input from other family members, even though this is a program targeted to infants and toddlers with special needs and their families. No state had recruited adult siblings of persons with disabilities or other family members to serve on the ICC. Research and professional practice, as well as family anecdotes, have consistently reported the importance that siblings have on one another (see, for example, Powell & Ogle, 1985). Furthermore, many children are cared for by someone other than a parent. Inclusion of

siblings and non-parent caregivers in this policy development phase might have added a new dimension to the proposed policies and practices.

States indicated the value they placed on the active participation of parents in state ICC activities by describing a wide variety of strategies by which to support this participation. While most offered reimbursement for travel and child care, some indicated additional or alternative ways to support parents.

One issue that was not addressed in this survey was discussed in a report on states' activities regarding ICC parents (Quest 1990). Parents who participate in ICC activities are often those who can afford to pay for the expenses and wait for reimbursement from the state. Perhaps a broader representation, a goal indicated by many of the Part H coordinators, could be achieved by providing some mechanism to pay for these activities without requiring reimbursement.

Parental Involvement & The EI System

There is no requirement in the law or the regulations for states to define "family." However, family strengths and needs are to be identified and services are to be provided to families. How will the IFSP team decide who will be considered a "family" member and which family members are entitled to receive services? Most states have at least begun discussion about who is in the family. A minority of states were caught somewhat off guard about the potential necessity to develop standards or guidelines about who is in the "family" and some said there would be no guidance from the state on this issue, leaving the decision at the local level.

When considering only those 32 states which had begun discussions about this topic, 78 percent indicated that they would define the family as anyone who the family says is a family. The rationale behind this could be

a need to be supportive of the family and to empower the family about some of these crucial decisions.

However, scenarios could be developed which might illustrate how this policy might result in confusion at the service delivery level. As an example, consider the following: I am a father of an eighteen month old child with special needs. I want my mother who is my child's babysitter to attend the IFSP meeting. Every state indicated that whoever the family wants to attend the meeting can, so this should be acceptable in each state. During the meeting I indicate that I want my mother to receive training in feeding practices. Is the child's grandmother legally entitled to receive training? What if the father had asked for mental health counseling for his mother because she has developed a negative attitude towards the child since the child's diagnosis?

Presumably, policies that state that the family is defined as anyone who the family says is family are designed to legitimize the family's right to recognize each family's special circumstances. Policies such as these may well result in obtaining this desired goal. However, some issues, as characterized in the scenario above, might need to be clarified if equitable services are to be provided to families across the state. Perhaps the states which have combinations of categories of family members, such as biological, and legal parents and persons who reside in the domicile and act as a parent, might prove to be more useful in guiding the implementation of this program. Questions such as these may only be able to be answered after this program goes into more wide-spread implementation at the local level.

One of the two areas that caused the most concern for Part H coordinators during this survey was identifying who would make a decision when the family requested services as "entitlements" but these

services were not typically provided or the request was for atypical amounts of services. The discomfiture of the coordinators appeared to be brought about because making decisions about the services to which a family is entitled has the potential to put the early intervention system in conflict with the family. If a family asks for an unusual type or amount of services someone will need to decide what is and what is not within the scope of the early intervention program.

The majority of Part H providers spoke of avoiding these dilemmas if at all possible because they want to support families, not oppose them. However, some conflict seems inevitable. In a recent study of due process cases for the school age population in one state, the great majority of the cases dealt with disagreements about services that were to be provided and listed in the Individualized Education Program (IEP) (EDLAW, 1990). Given this history, which is not atypical in many other states, conflict over type or amount of services would seem to be at least a possibility.

While the survey indicated that half the states said that the IFSP team will resolve such conflicts, data were not collected about how the team will make such decisions. Will the team vote and the majority prevail? Will some representative from the lead agency be assigned a role which includes some veto power? How can services that are to be provided by other agencies than the lead agency be authorized at the IFSP meeting if such agencies do not have representation at the IFSP meeting? These and other questions will need to be decided at the state level if decision-making is to be consistent throughout the state. Further investigation is necessary to determine how states are or will deal with these complex and sensitive issues.

Policies in the states that did not describe back-up mechanisms for review and resolution of such systems could lead to a service delivery

system that is very supportive of families. This might occur because the team is empowered to make decisions, with the parent being an essential member of the team. On the other hand, if a family disagrees with the team's decision, in these states the family's only recourse is to become involved in the state's formal or informal complaint resolution system.

In those states where there is a process, following the team's meeting, to resolve disputes of the team, states and families will have recourse to another level of review. Again, the effect of this policy in terms of optimizing services to families cannot be determined at this time. A back-up system of review might provide a forum where decisions can be made by people who may be more removed from the situation, who might be more impartial, or who might have had different experiences and knowledge than the team. If such is the case, the family might be well served by having this vehicle for review available to solve disputes. However, if this system results in decisions which are consistently unfavorable to the family or demonstrate some bias, this step might add a needless delay in the resolution of the dispute. Continued implementation of each of the policies described in the survey will be necessary in order to determine the success of the policy options being considered by the various states.

In summary, states have undertaken, with apparent enthusiasm and zeal, a mammoth set of tasks for developing a statewide, comprehensive, coordinated, interagency, multi-disciplinary early intervention program to meet the unique needs of infants and toddlers with special needs and their families. This CPSP survey demonstrates that significant activity is occurring in each state to develop a system that will work in partnership with families to meet the needs of these very young children.

APPENDIX A

METHOD

As part of the family policies study, the National Association of State Directors of Special Education (NASDSE) conducted a second telephone survey of state Part H coordinators to identify the status of policies affecting families. This study was conducted as part of the sub-contract awarded to NASDSE by the Carolina Policy Studies Program (CPSP) at Frank Porter Graham Child Development Center, the University of North Carolina.

Input was solicited from the CPSP Family Advisory Board and state Part H coordinators to develop a draft survey protocol. In the spring of 1990, the draft was sent to the Family Advisory Board and selected Part H coordinators for review. These measures assured that the information to be collected was important and relevant to those who will be the primary recipients of the analysis.

During the summer of 1990, the survey protocol was mailed to all state Part H coordinators in 50 states and the District of Columbia. (The District of Columbia will be referred to as a state in this report.) Coordinators were called to schedule the one hour survey call at their convenience. After some initial calls it became apparent that additional clarification on a few items would contribute information that would be useful to states. Therefore, it was decided that some questions would be added to the original protocol despite the fact that these data would not be available from every state because some interviews had already been conducted. Whenever data are presented from less than the total number of states, such information is noted in the text. Verbal responses were coded and the categorized responses were sent back to each coordinator

for verification. Changes or corrections to these categorizations were made prior to the final data analysis. .

All states participated except one. That state sent a letter declining participation because they did not have family policies and so could not respond to the items in the survey. For some analyses, states were categorized as having the State Education Agency (SEA), Health, or other as the lead agency. A category of "other" lead agencies was created because categorizing these agencies further might jeopardize their anonymity. The SEA was the Part H lead agency in 18 states that participated in the survey, Health was the lead agency in 14 states, and some other agency was the lead agency in 18 states.

The survey collected information in four areas of policy development most relevant to families: parent involvement on the Interagency Coordinating Council (ICC), selected components regarding access to the early intervention system, case management, and procedural safeguards. These topics were selected because they particularly involve or affect the families of infants and toddlers with special needs.

These topics have emerged as the significant issues through interviews with state agency personnel and families during CPSP case study interviews. In addition, the family advisory board substantiated that these were topics on which data should be collected.

Family involvement on the state ICC may influence the nature of policies and program practices for all families involved in early intervention. The first contacts between the family and the early intervention program may set the tone for all future interactions and so identifying the policies and mechanisms which are to be used by families to enter the system were an important area of study for this survey. Identification of the family's strengths and needs can be a very positive

experience if approached with a sense of partnership and support for families (Johnson, McGonigel, & Kaufmann, 1989) or can be unnecessarily intrusive. Therefore, these policies have an important place in this survey.

The same caution can be made about case management and so the nature and procedures of the case management system were important to study as states begin to refine or develop this system. Decisions about services to be included on the IFSP will critically impact on the families receiving these services and so several questions addressed this topic. Finally, procedural safeguards must be studied to identify what policies will be available to protect a family's right to privacy, to assure that the family is the authority and primary decision-maker, and to provide a vehicle for resolving disputes.

All these topics were addressed in the CPSP survey. Because of the quantity of data collected, these results have been presented in three separate reports. This report, Status of States' Policies that Affect Families: The Early Intervention System, deals with the ICC and the family, parental access to services, the identification of family strengths and needs and family participation at the IFSP meeting. The second report, Status of States' Policies that Affect Families: Procedural Safeguards, deals with policies regarding consent, confidentiality, access to records, and dispute resolution. The final survey report, Status of States' Policies that Affect Families: Case Management, deals with the selection of case managers, qualifications and training of case managers, vehicles to monitor and supervise case managers and financing the case management system.

Given the current status of policy development in the states, most of the policies identified in this report fall somewhere short of being

"official" policy. These policies might represent a recommendation by the ICC or by the lead agency or might be current practice. When a policy has been formally adopted by a state it is identified as an official policy.

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